

Consumer Guide

Early HIV Infection

HIV and Your Child

Office of Minority Health
Resource Center
PO Box 37337
Washington, DC 20013

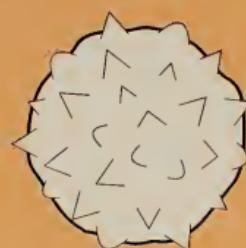


**Clinical Practice Guideline
Number 7**

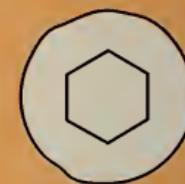
MH-7509465

The Immune System and HIV

The body's health is defended by its immune system. White blood cells called lymphocytes (B cells and T cells) protect the body from "germs" such as viruses, bacteria, parasites, and fungi. When germs are detected, B cells and T cells are activated to defend the body.



Lymphocyte



Human immunodeficiency virus—HIV

This process is hindered in the case of the acquired immunodeficiency syndrome (AIDS). AIDS is a disease in which the body's immune system breaks down. AIDS is caused by the human immunodeficiency virus (HIV).

When HIV enters the body, it infects special T cells, where the virus grows. The virus kills these cells slowly. As more and more of the T cells die, the body's ability to fight infection weakens.

A person with HIV infection may remain healthy for many years. People with HIV infection are said to have AIDS when they are sick with serious illnesses and infections that can occur with HIV. The illnesses tend to occur late in HIV infection, when few T cells remain.

Where did HIV and AIDS come from?

We may never know where or how HIV and AIDS began. Many experts believe that AIDS was present in the United States, Europe, and Africa for several decades or longer before the earliest cases appeared in 1980 and 1981.

HIV was first identified in 1984 by French and American scientists, but the human immunodeficiency virus did not get its name until 1986.

HIV and Your Child



Purpose of this Booklet

Even before HIV causes AIDS, it can cause health problems. Learning about how the virus can affect your child's body and getting care early, before health problems worsen, can help your child live a longer and healthier life.

This booklet is a guide to understanding HIV and getting the right care for your child. It gives you questions to ask your doctor, nurse, or other medical care provider. What you learn about HIV and AIDS will help you become more involved in your child's health care.

HIV affects everyone in a family, whether only one or several family members are infected. Babies with HIV and their infected parents need to be followed very closely by a

medical care provider such as a doctor, nurse, or other medical professional.

Babies who may have HIV infection should be tested for HIV as soon as possible after birth and have regular followup exams. This is very important to help your baby stay as healthy as possible.

Facts About HIV in Babies and Children

- HIV can be passed to a baby during pregnancy or delivery.
- An HIV-infected woman's chances of having a baby with HIV are one in four (25 percent) for each pregnancy.
- HIV can be passed to a baby through breast milk from an HIV-infected mother.
- Like adults, children and adolescents can get HIV from contact with blood or body fluids or through sex.
- Bathing, kissing, feeding, and playing with your child are not risky and do not cause the spread of HIV.
- In the past, some babies and children became infected through blood transfusions. Today the blood from all donors is screened for the virus, and HIV infection from this source is unlikely.
- Special blood tests can show whether your infant is infected with HIV.
- Your child needs to see a health care provider who has experience treating HIV-infected babies and children.
- Early immunizations (shots) can help protect your child from other HIV-related diseases.

How will I know if my baby has HIV?

Before a baby is born, it shares its mother's blood supply. If you are infected with HIV, you can transmit HIV to your child through your blood before birth. The baby also can become infected during delivery.

For the first few months, your baby may test positive for HIV infection because it still has some parts of your blood, so early tests are not accurate. After several months, the child's own system takes over. Test results then become accurate for your child and can indicate HIV infection.

When your child is less than 2 years old, his or her blood should be tested every 2 to 3 months until the system matures. After age 2, a single blood test can show if your child is infected with HIV.

What will happen to my baby?

Some babies who have HIV infection may become ill in the first year of life. Others remain healthy for many years.



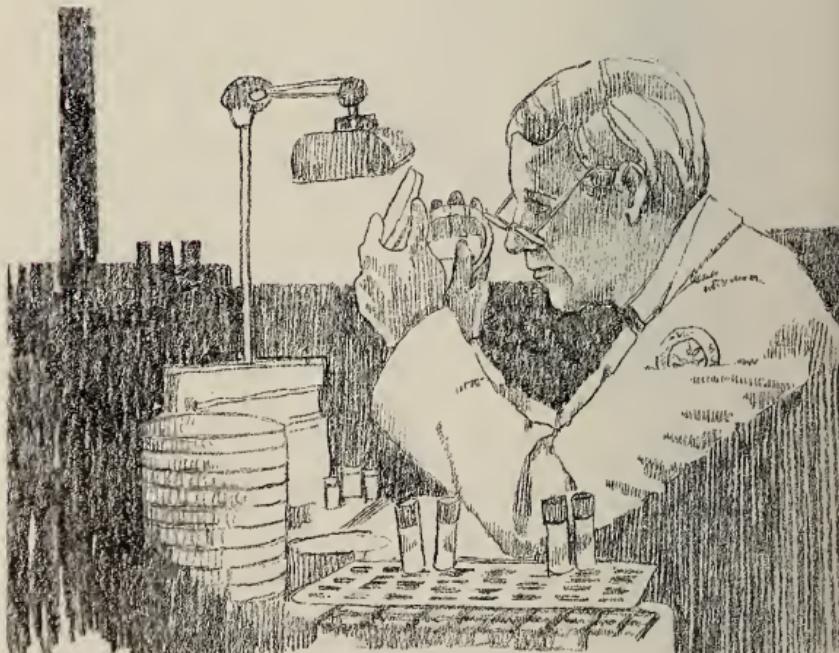
Regular medical checkups and blood tests will help your doctor keep track of how your child is doing and decide whether special medicines are needed. Ask your health care provider how you can help protect your child.

How can I help my child stay healthy ?

It is very important to seek medical care as soon as you know that your child has HIV. Although there is no cure as yet for HIV, there are things you can do to help your child stay as healthy as possible.

Because your child has HIV infection, you will want to learn as much as you can about the virus. You can prevent many illnesses by:

- Keeping your home safe and clean.
- Observing and listening to your child.
- Telling your health care provider right away about unusual behavior or symptoms.
- Working with the doctor, nurse, or other health care provider to plan your child's care.
- Making sure your child gets all recommended baby shots and booster shots.
- Try to keep a positive outlook. Hope is very important. Every day, there are new drugs and treatments for HIV that may help your child. Each time you take your child for health care, be sure to ask about new treatments or clinical trials that might be right for your child.



1

Prevent Illness

Immunize Against Infection

With HIV infection, your child is more likely to get common childhood illnesses, and these may be more serious. You can protect your child by making sure all the baby shots are given on time. These shots include:

- Diphtheria, pertussis (whooping cough), and tetanus (DPT).
- Polio (IPV).
- Mumps, measles, rubella (MMR).

Your health care provider may recommend other immunizations, depending on the results of medical tests. These include:

- *Haemophilus influenzae* type B (Hib)
- Hepatitis B (HepB)
- Pneumococcal infection (after 2 years of age)
- Influenza (yearly)

Avoid Common Illnesses

Some infections cannot be prevented by shots. Infections from the bacteria and viruses that cause sores, colds, and influenza (flu) can weaken your child and make it harder to resist more serious HIV-related diseases. Keep your child away from people who are sick, and tell the doctor or nurse if you think your child has been near someone with tuberculosis (TB) or other infections.

2

Provide a Healthy Home Life

As the parent or guardian of a child who has HIV infection, you will want to take special care of yourself so that you can care for your child. The advice that follows can help both you and your child stay as healthy as possible.

Teach personal care. Wash your hands often, and teach your child to do the same as soon as he or she is able. Keep your child away from human or animal waste.

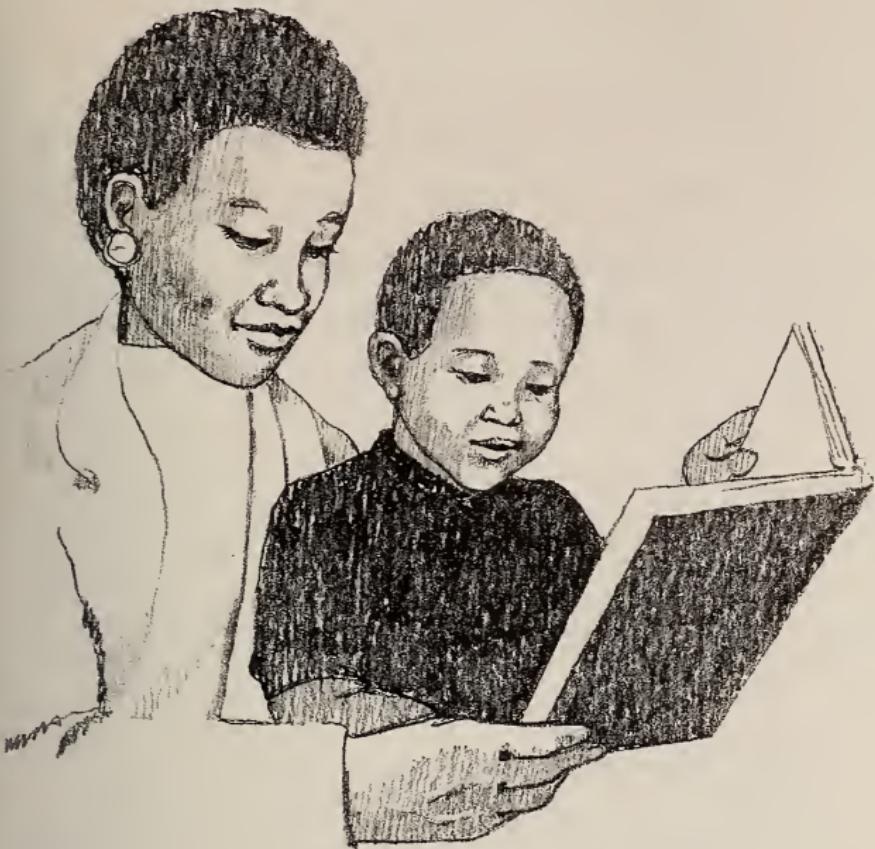
Brush the child's teeth until he or she is able. Your child will need to visit the dentist twice a year. Ask the dentist to help you teach your child proper mouth care. The first sign of your child's HIV infection may be sores in the mouth. At each visit, the doctor or nurse will examine your child's mouth.

Eat healthy foods. Your child needs healthy foods in order to grow and to help fight infections. A proper diet will also help you and your child have strength and energy. Your child's health care provider can help you decide which foods are best. Ask how to help a "picky eater" learn to enjoy healthy foods.

Get regular exercise. Most children with HIV infection are active; however, some need encouragement to get physical exercise (in fresh air and sunshine if possible). Regular exercise is important to help you and your child keep up your strength.

Get plenty of sleep. HIV-infected children need rest. Sleep will renew your child's energy for the next day, especially for going to day care or school, where there may be little time for rest during the day.

Play with, talk to, and hug your child often. Spending time together will help you spot problems that should be reported to your child's health care provider.



Give medication correctly and on time.

Your child needs medicines to slow the HIV infection and prevent other infections, such as pneumonia, that can occur when the immune system is weak.

Your doctor or nurse will tell you exactly what medicine your child should have. Giving your child the right amount of medicine, and giving it on time, can mean the difference between staying healthy and becoming severely ill.

Do not allow your child to take any other medicines, alcohol, or illegal (street) drugs.

See the back of this booklet for some helpful hints on giving medicine to a young child. Your child's health care provider can show you how to hold the baby and use medicine droppers or syringes correctly.

Help your child lead a normal life.

Playing with other children in your home and in the neighborhood is good for your child. It is not dangerous for your child or for the other children. HIV infection is not spread by touching or being in close contact with a friend.

3

Report Symptoms Promptly

Watch your child carefully. Report any of the following to your health care provider right away:

- Fever.
- Cough.
- Fast or difficult breathing.
- Loss of appetite and poor weight gain.
- White patches or sores in the mouth.
- Diaper rash that won't go away.
- Blood in the diaper or bowel movements.
- Diarrhea (frequent loose, watery, bowel movements).
- Vomiting.
- Contact with a person who has chicken pox, measles, TB, or other diseases that can spread.

4

Be Sure Your Child Gets Medical Treatment

Your child may stay strong and healthy for a long time, but to be sure, regular blood tests will be needed to show how well the immune system is working.

Special T cells, called CD4 cells, in the blood help the body defend itself from attackers, such as viruses. But CD4 cells can be destroyed as your child's HIV infection worsens, leaving your child unable to fight off other infections and illnesses.

Your child's health care provider will do a CD4 cell count every few months. This test shows the number of CD4 cells in your child's blood and lets the doctor know when special medicine is needed.



The doctor will probably prescribe medicine, such as AZT (now called ZDV, for zidovudine), didanosine (ddI), or dideoxycytidine (ddC) to help slow your child's HIV infection.

Another drug, trimethoprim-sulfamethoxazole or TMP-SMX (Bactrim®, Septra®, and generic products), may be given to prevent *Pneumocystis carinii* pneumonia (PCP). PCP is the most common serious pneumonia in children with HIV. Your child may need other medicines to prevent "opportunistic" infections that can take advantage of a weakened immune system.

These treatments are strong and can cause problems. Watch for and report side effects such as problems in sleeping, headaches, vomiting, muscle or belly pain, numbness in hands or feet, or hyperactivity.

Your health care provider will take blood tests regularly to see how well your child can resist infections. Be sure to ask your doctor about other tests and treatments your child may need, including:

- New HIV drugs or vaccines. New medicines are tested on people to see if they are safe or helpful. This is called a clinical trial. Usually, new HIV medicines must be tested in a clinical trial before a doctor can give them to patients who are not part of the clinical trial.
- Special x-rays and other tests for growth, development, and nervous system function.
- Special feedings or formulas.
- Physical, occupational, or speech therapy.

Signs and Symptoms of HIV Infection in Babies

- Swelling in the lymph glands in the neck, under the arms, and in the diaper area
- Swollen belly, sometimes with diarrhea (frequent loose, watery, bowel movements)
- Itchy skin rashes
- Frequent lung infections (pneumonia)
- Frequent ear and sinus infections
- Problems with gaining weight or growth
- Inability to do the kinds of things healthy babies do (such as sitting alone, crawling, walking)
- Crankiness, irritability, and constant crying

Most important, talk with your health care provider right away about anything you notice that seems unusual for your baby.

Telling Others About Your Child's HIV Infection

When you learn about your child's HIV infection, you may have mixed feelings, including fear, anger, sadness, or guilt. Telling people that your child has the virus may be hard. You will need to think about many things when deciding whom to tell about your child's HIV infection.

Talking About Your Child's HIV Infection

Possible Benefits

- More support from family and friends
- In some states, better health and welfare benefits
- More acceptance of the child's infection

Possible Risks

- Rejection by family, friends, or day care, school, or social programs
- Changes in health benefits

Although it is risky, sharing information about your child's HIV infection can be helpful in a number of ways. Telling others may help you seek the medical care your child needs and apply for other kinds of help. You can begin actively planning for your child's care and your family's future.

Your doctor, nurse, social worker, or other members of the health care team can help you plan how and when to share information about your child's HIV infection. They can help you tell others. Your list of people to tell may include:

- Your child, if he or she is old enough to understand.
- Family members.
- Day care workers or babysitters.
- Teachers, classmates, and other people at school.
- Health professionals who work with your child or your family, including your family doctor and dentist, nurses, social workers, nutrition counselors, and pharmacists.

Your doctor may be required by law to report your child's HIV infection to the state or local health department. Ask about the laws, confidentiality, and anonymous HIV testing in your state.

Talking with Your Child About HIV Infection

Consider your child's age. Talk with your child about HIV when he or she seems ready, possibly around age 5. How you talk with an older child about HIV infection depends on whether the child has had HIV since infancy or is newly diagnosed.





Young children. Children born with the virus have learned a lot about living with HIV infection by the time they reach the age when they can understand what it means to have HIV. Your child will have had regular visits to doctors and other health care providers and will have experienced blood drawing and shots. Taking medicines may be routine. Perhaps your child knows or can say the name of the infection, too.

Young children are usually content with knowing only a little bit about HIV. You can give short, simple answers to most of the questions your young child asks.

School-age children. Older children can understand much more. It is very important to give your child correct information and honest answers about your feelings. Otherwise the child may get the wrong information from someone else.

A child who has HIV infection that is kept secret may suffer silently because of shame or fear. An older child who is having trouble coping with HIV infection may:

- Have problems sleeping.
- Pull away from friends and family.
- Be depressed or sad.
- Have problems at school.

Even a young child may have many of the same problems as an adult when dealing with HIV infection. Counselors and health care providers who work with children who have HIV can help you recognize changes in your child's behavior. They can help the child, and you, find ways to talk about these problems.

Older children. The older child—from 12 to 21 years of age—who has recently become infected with HIV may feel and express many of the same emotions as an adult in the same situation: disbelief, fear, sadness, depression, shame. At the same time, the child may behave in some of the same ways as a younger child.

Learning as much as possible about HIV and AIDS will help you talk with your child. For example, your child may ask (or might like to ask):

- Am I going to get sick? When?
- What will happen to me?
- Will I have to go to the hospital or see the doctor more often?
- How will HIV affect my family, friends, and people at school?
- How can I prevent giving HIV to others?

It is important to talk with older children who have HIV about using condoms for safe sex, as well as the dangers of needle-sharing. It may be very hard to stay calm and neutral when talking with your older child about HIV infection. You may want to arrange for your child to meet privately with an HIV/AIDS health counselor who knows how to interact with teenagers. Ask your child's health care provider to help you find a counselor who can meet with your child.

Talking with your older child in an open and friendly way will do much to ease fears about rejection by other family members and friends. You may decide together whom to tell about the HIV infection and when.

How can we get the support our family needs?

A person or family with HIV may need many kinds of support. Your child's health care provider and your local health and social services departments can assist you in finding the help you need. Help may include someone to:

- Answer your questions about HIV and AIDS.
- Help you find health care providers and make health care decisions.
- Provide transportation to and from health care appointments.
- Assist in planning ways to meet financial and daily needs.
- Arrange home nursing care or rehabilitation services.
- Refer you and your loved ones to support groups.
- Represent your family in legal matters.

Sometimes it helps to talk with others who also have HIV or a child with HIV. Here are some ways of finding them:

- Read HIV newsletters.
- Join a support group for friends and family.
- Volunteer to help others.
- Attend social events to meet other families living with HIV.

Additional Resources

There are many ways to get information about living with HIV. You may find it helpful to read about HIV and learn how others have cared for themselves or their family members.

- You can get information from your local health department about HIV, including where to get tested for the virus and the kinds of services available to your child and your family.
- Your local or state medical society can help you find a doctor.
- Your library may have information that you can share with your child. Ask your librarian if there is a special directory that lists groups for families whose children have HIV.
- Some hospitals and churches offer programs and sponsor support groups.

National hotlines and information clearinghouses can send you free publications and give you the latest news about drug-testing and clinical trials. Here are some telephone numbers to help you get the information you need:

General Information

National AIDS Hotline

- English(800) 342-AIDS (2437)
Spanish(800) 344-SIDA(7432)

TDD Service for the Deaf

(800) 243-7889

National AIDS Clearinghouse

(800) 458-5231

National Pediatric HIV Resource Center

(800) 362-0071

HIV/AIDS Treatment Information

American Foundation for AIDS Research
(800) 39AMFAR (392-6327)

AIDS Treatment Data Network
(212) 268-4196

Project Inform (800) 822-7422

Clinical Trials Conducted by the National Institutes of Health or Food and Drug Administration-Approved Trials:

AIDS Clinical Trials Information Service
800-TRIALS-A (874-2572)

Social Security Disability Benefits

For confidential assistance in applying for social security disability benefits, call the Social Security Administration at (800) 772-1213. You may request a personal earnings and benefit estimate statement (PEBES) to help you estimate the retirement, disability, and survivor benefits payable on your social security record.

**Start your own list of services,
support groups, and where to
get information now:**

Hints for Giving Medicine to Babies and Toddlers

Giving medicine to your baby or young child does not have to be a chore for either of you. Just follow these steps:

1. Prepare the medicine and place it and other things you will need on a table within reach of the hand you will feed with.
2. Hold the baby on your lap. If you are right handed, hold the baby on your left (if left handed, on your right).
3. With your left hand, hold baby's left arm; baby's right arm should go under your left arm, around your back.
4. Support baby's head and shoulder firmly between your left arm and chest, and tilt the head back a little bit.
5. Squirt small amounts of medicine into the side of the baby's mouth alongside the back of the tongue on the side closest to your body (baby will have a hard time spitting and will not choke).
6. Keep baby's mouth closed and hold baby's body upright until the medicine is swallowed.

Helpful Hints:

- For liquids, use a soft plastic dropper or syringe.
- Try mixing medicine in food for spoon-feeding.
- Sit in a firm, comfortable chair.
- Put a bib or towel on baby.
- Stay calm and use a soft voice.
- Reward baby with juice or water to rinse the mouth.



For Further Information

The information in this booklet was taken from the Clinical Practice Guideline on Evaluation and Management of Early HIV Infection. The guideline was written by a panel of private-sector experts sponsored by the Agency for Health Care Policy and Research. Other guidelines on common health problems also are being developed.

To order another copy of this booklet, call the National AIDS Hotline toll-free at **(800) 342-AIDS**, or write to:

AHCPR HIV Guideline
CDC National AIDS Clearinghouse
P.O. Box 6003
Rockville, MD 20849-6003

To order copies of AHCPR-sponsored guidelines on other topics call **(800) 358-9295** (for callers outside the U.S., only: (301) 495-3453) weekdays, 9 a.m. to 5 p.m., Eastern time. Or, write to:

Agency for Health Care Policy and Research Publications Clearinghouse
P.O. Box 8547
Silver Spring, MD 20907



U.S. Department of Health and Human Services
Public Health Service
Agency for Health Care Policy and Research
Executive Office Center, Suite 501
2101 East Jefferson Street
Rockville, MD 20852

AHCPR Publication No. 94-0576
January 1994